

**Perspectives of Hospitalized Children and Parents on the
Quality of the Children's Nursing Care**

Trisha Horstman, Senior Honors Nursing Student
The Ohio State University
horstman.67@osu.edu

(Please direct communications to above address)

Nancy A. Ryan-Wenger, PhD, RN, CPNP, FAAN
Director of Nursing Research
Nationwide Children's Hospital
700 Children's Drive
Columbus, OH 43205
Nancy.Ryan-Wenger@nationwidechildrens.org

Abstract

Three million children are hospitalized annually, yet large-scale research is sparse on children's perceptions of their hospital experiences. Parents routinely receive and complete post-discharge "patient" satisfaction questionnaires. Yet, research shows that children's and parents' perceptions of children's emotions and experiences are often dissimilar. **Purpose:** 1) Identify characteristics of nursing care that are most important to hospitalized children; 2) Compare hospitalized children's and parents' perspectives on quality of nursing care and children's current quality of life. **Subjects:** The sample included 496 children, ages 6 to 21, in a 400-bed children's hospital (73% white, 20.29% black). **Methods:** A cross-sectional research design involved individual interviews with children about what they liked and disliked about their nursing care, and responses to the 6-item Pediatric Quality of Life-Present Functioning (PEDS-QL-PF) Scale. Independently, parents answered the same questions as they believed their *children* would respond. **Findings:** Parents consistently underestimated what their children would say about their nurses. Children reported 10 nurse behaviors more often than parents: checks on me often, talks and listens to me, gives me medication, gives me things to do, responsive to my needs, brings me food or drinks, helps me do things, plays with me, laughs and jokes with me, and gives me respect and privacy (all $p < 0.05$). Children reported 3 of 7 nurse behaviors that they disliked more frequently than parents including uncomfortable procedures, painful experiences, and wakes me up (all $p < 0.001$). Parents mentioned no nurse behaviors significantly more often than their children. Fewer children than their parents reported experiencing six PEDS-QL-PF items: afraid, sad, angry, worried, tired, and pain (all $p < 0.001$). **Implications:** Children and parents disagreed on the importance of 10 of 14 nurse behaviors that children said they liked and 3 of 7 nurse behaviors that they disliked. Parents consistently overestimated their children's current

symptoms and emotions. Nursing assessments that include quality of care and current quality of life from the children's perspectives will greatly enhance the children's hospital experiences.

Chapter I

Introduction

Three million children are hospitalized annually, yet large-scale research is sparse on children's perceptions of their hospital experiences. Parents routinely receive and complete post-discharge "patient" satisfaction questionnaires while children are rarely asked to evaluate their own care. Research shows that children's and parents' perceptions of children's emotions, symptoms, and experiences are often dissimilar. This study was designed to evaluate children's perceptions compared to their parents.

Purpose

The purpose of this study was to:

1. Identify characteristics of nursing care that are most important to hospitalized children.
2. Compare hospitalized children's and parents' perspectives on quality of nursing care and children's current quality of life.

Theoretical Framework

The underlying theoretical framework for this study was ecological momentary assessment (Stone & Shiffman, 1994). Data about a person's mood, physiologic status, and/or behaviors are "assessed in real time, repeatedly, and in everyday life situations" (aan het Rot, Hogenelst, & Schoevers, 2012, p. 511). This method avoids recall bias when information is requested after an event.

Chapter II

Review of Literature

Parent-child agreement on whether or not children had behavioral problems ranged from 8% to 38% in a study that examined the agreement between children and parents on rating the children's behavior problems using the parent-rated Child Behavior Checklist and child-rated Youth-Self Report (Martin, Ford, Dyer-Friedman, Tang, & Huffman, 2004). Authors found that 32.8% (n=90) of children reported that they have behavior problems, compared to 63.5% (n=174) of parents. Agreement between the parent and child on existence of behavior problems was 24.8% (n=68), and agreement on absence of behavior problems was 28.5% (n=78). Disagreements in which the child reported behavior problems, but not the parent occurred in 8% (n=22) of the sample, while disagreements in which the parent reported behavior problems but not the child occurred in 38.7% of the sample. There were no differences in agreement for gender of the children ($\chi^2=2.3$, $p=0.53$).

Parent-child agreement measured by correlations ranged from $k=0.23$ to 0.66 in three studies and $r=0.38$ in another study. In one study the correlation between a diagnostic questionnaire completed by parents and children for post-traumatic stress disorder (PTSD) and an actual diagnosis of PTSD from clinical psychiatric interviews was analyzed (Shemesh et al., 2010). A total of 86 children and adolescents ages 8 to 19 years old and parents were both given different forms of the UCLA Posttraumatic Stress Reaction Index (PTSRI) to determine if one group were predictive of an actual diagnosis of PTSD in the child with the PTSRI. The children's above-threshold scores on the PTSRI were significantly related to a diagnosis of PTSD ($k=0.221$, $p=0.050$) while the parent's scores were not ($k=0.124$, $p=0.266$).

Petsios et al. (2011) evaluated levels of agreement between children and parents in rating the health related quality of life (HRQoL) of children with asthma measured by instruments devised by the authors. On 7 of 9 subscales, children had lower HRQoL scores (range 53.3 ± 10.2 to 86.4 ± 16.9) compared to parents (range 60.9 ± 12.7 to 90.2 ± 11.8 , $p < 0.001$). The level of agreement in parent and child scores was significant at 0.480 ($p < 0.001$). The fathers' assessment of the children's HRQoL was closer to their child's report than the mothers' (ICC=0.581 versus ICC=0.448 respectively); which reflects moderate to good parent-child agreement on the children's HRQoL.

Nauta et al. (2004) researched the effectiveness of the parent version of the Spence Children's Anxiety Scale (SCAS-P), but also reported data related to parent-child agreement in a total sample of 745 children ages 6 to 18 years old. Parent-child agreement on subscales of the SCAS-P was greater among 484 children with a diagnosis of anxiety disorder ($k=0.41-0.66$, $p < 0.001$) than among 261 children without an anxiety disorder ($k=0.23-0.60$, $p < 0.001$).

In another article the relationship between mothers' and children's satisfaction regarding mental health services was measured by Client Satisfaction Questionnaire (CSQ-8) (Copeland, Koeske, & Greeno, 2004). Children ($n=147$) were ages 8 to 17 years old. The overall correlation between mothers' and children's scores was $r=0.38$, $p < 0.001$ ($\bar{x}=3.18 \pm 0.82$ versus 3.07 ± 0.77).

One study measured parent-child agreement by comparing means on satisfaction with pediatric emergency room visits (Margaret, Clark, Warden, Magnusson, & Hedges, 2002). Margaret et al. (2002) researched the satisfaction of 101 children ages 5 to 17 years old and their accompanying parents in a pediatric emergency room setting. Child satisfaction ($\bar{x}=0.80$) was significantly lower than parent satisfaction ($\bar{x}=1.55$) in children ages 5 to 11 years old ($z=-3.21$,

$p=0.001$). Children 12 to 17 years old reported lower mean scores than their parents, but they were not significantly different ($z=-0.51$, $p=0.61$).

In summary, it is clear that children's and parents' perceptions are very different in other settings. Further research is needed with a focus on hospitalization.

Chapter III

Design

This cross-sectional, secondary analysis study is based on data from a larger study funded by the Robert Wood Johnson Foundation, Interdisciplinary Nursing Quality Research Initiative (#62575, Principal Investigator, Ryan-Wenger). Data were collected from 496 hospitalized children and their parents in a large free-standing children's hospital (Ryan-Wenger & Gardner, 2011). The hospital was accredited as a Magnet hospital by the American Nurses Credentialing Center.

Procedure

The study was approved by the hospital's Institutional Review Board. Parental consent, patient consent, or child assent was obtained depending upon the age of the patients. Patients were asked to respond to two questionnaires about their present functioning quality of health, and anxiety and depression symptoms. This was followed an open-ended interview schedule in which children were asked what they liked and disliked about their nursing care. Parents independently completed the quality of health scale and the quality of nursing care questions as they thought their children would respond.

Sample

The sample included 496 hospitalized children ages 6 to 21 years, and their parents. Inclusion criteria were English-speaking, developmental age of at least 6 years, and admitted to the hospital for more than one day.

Instruments

Instruments included a Demographic and Clinical Data Form, the Pediatric Quality of Life – Present Functioning Scale (PedsQL-PF), the Revised Children's Depression and Anxiety

Scale (RCADS), and a structured open-ended interview schedule. Demographic data included age, gender, race, median household income based on zip code, diagnoses, admission and discharge dates, number of days hospitalized at the time of the interview, number of invasive procedures experienced prior to the interview, and number of previous hospitalizations.

The PedsQL-PF (Sherman, Eisen, Burwinkle, & Varni, 2006) includes 6 items: feeling anxious, sad, angry, worried, tired, and pain scored on a scale of 0 to 4 (0= not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit, 4= very much). The original format of a 0 to 100 mm visual analog scale (VAS) was revised to this ordinal scale by Varni and colleagues. Internal consistency reliability of the original scale was 0.72 to 0.84. Construct validity was supported by correlations ranging from 0.37 to 0.60 ($p < 0.01$) between the four-item Emotional Distress scale, and fatigue scores with the Pain VAS scores.

The RCADS (Chorpita, Moffitt, & Gray, 2005) is a 47-item scale that measures six aspects of anxiety and depression: separation anxiety, generalized anxiety, panic disorder, social phobia, obsessive-compulsive disorder, and depression. Items were scored on a scale of 0 to 3 (0 = never, 1 = sometimes, 2 = often, 3= always). Internal consistency reliability ranged from 0.71 to 0.85. High correlations between RCADS and the Children's Depression Inventory ($r = 0.65$ to 0.80) and the Spence Children's Anxiety Scale ($r = 0.65$ to 0.82) demonstrated construct validity.

An investigator-developed open-ended structured interview was based on theory, literature, and clinical experience to measure hospitalized children's perceptions of their nursing care. This study is based on children's and parents' responses to two of the questions: 1) What do you like most about your nurses and what they do for you? 2) What don't you like about your nurses and what they do for you? Responses were sorted into 15 different categories.

Data Analysis

Children's and parents' open ended responses to the questions about nurse behaviors were inductively sorted into similar categories. Comparisons between children's and parents' reports about nurse behaviors that children liked and disliked were analyzed by chi-square. The differences between children who reported nurse behaviors compared to children who did not were analyzed by Mann-Whitney U tests for interview day, invasive procedures, number of previous hospitalizations, and median household income. T-tests were used to evaluate differences in RCADS total and subscale scores according to nurse behaviors that children liked and disliked. The relationship between children's responses and four variables that may have influenced their responses, including interview day, invasive procedures, number of previous hospitalizations, and median household income were evaluated by Wilcoxin signed ranks tests.

Chapter IV

Research Results

The ratio of male to female children who participated in the study was fairly equal (49.2% to 50.2% respectively) (Table 1). The race of the sample was reflective of the hospital's population (white 73%, black 20.2%). The most common diagnostic category was gastrointestinal (n=128, 25.8%), followed by neurology (12.5%), hematology/oncology (10.9%), and pulmonary (10.5%). The children were categorized into five developmentally appropriate age groups (Figure 1).

Parents consistently underestimated what their children would say about their nurses. Children reported 10 nurse behaviors more often than parents: checks on me often, talks and listens to me, gives me medication, gives me things to do, responsive to my needs, brings me food or drinks, helps me do things, plays with me, laughs and jokes with me, and gives me respect and privacy (all $p<0.05$) (Table 2). Children and parents agreed on four nurse behaviors that children liked: nice and friendly, takes care of me, cares about me, and makes me comfortable. Children reported 3 of 7 nurse behaviors that they disliked more frequently than parents including uncomfortable procedures, painful experiences, and wakes me up (all $p<0.001$). Children and parents agreed on four nurse behaviors that they disliked, including not responsive to my needs, doesn't talk or listen to me, not nice or friendly, and no respect or privacy. Parents mentioned no nurse behaviors significantly more often than their children. Parents overestimated their children's symptoms on the Peds-QL for all of the items (Table 3, Figure 2). Fewer children than their parents reported experiencing six PEDS-QL-PF items: afraid, sad, angry, worried, tired, and pain (all $p<0.001$).

Total Peds QL scores were lower for children who liked nurses giving them medications than children who didn't mention medications (Median = 2 vs. 3, $z=2.234$, $p=0.025$). Total Peds QL scores were higher for children who said that nurses were not responsive to their needs (Median = 4 vs. 3, $z=2.888$, $p=0.004$). Children with lower T-scores for obsessive-compulsive disorder said that they liked nurses who laughed and joked with them more often than children who did not mention this nurse behavior ($p=0.025$); obsessive-compulsive T-scores were higher for children who said they disliked nurses who were not nice or friendly ($p=0.047$), and nurses who don't talk or listen to them ($p<0.001$) compared to children who did not mention these nurse behaviors (Table 4).

The relationship between children's responses and four variables that may have influenced their responses, including interview day, invasive procedures, number of previous hospitalizations, and median household income were evaluated by Wilcoxin signed ranks tests. Children who reported liking the fact that nurses gave them medications had fewer number of invasive procedures than children who did not ($z = 18.3$, median=2 vs. 4, $p<0.001$). Wakes me up was reported significantly more often by children from families with a higher median household income of compared to children who did not report that nurse behavior ($z = 19.2$, median \$42,009 vs. \$37,363, $p<0.001$). Interview day, defined as the percentage of total length of stay completed at the time of the interview, and number of previous hospitalizations were not significantly related to any of the children's likes and dislikes about their nursing care ($p=0.066$ to 0.997).

Chapter V

Discussion

This is the first study to compare children's and parents' perspectives about the children's nursing care. The large sample (N=496) from this free standing children's hospital is representative of most hospitalized children because of the wide range of diagnoses, age, and median household income. The racial distribution was 73% white and 20.2% black.

Our findings that children's and parents' perceptions differ significantly are consistent with other studies of different settings, diagnoses, and topics, such as health related quality of life in children with asthma (Petsios et al., 2011), behavior problems (Martin et al., 2004), PTSD symptoms (Shemesh et al., 2010), satisfaction with mental health services (Copeland et al., 2004) and satisfaction with pediatric emergency department visits (Margaret et al., 2002). In our study differences between children and parents report of the children's PEDS QL symptoms were highest for sad (27.8%), afraid (26.1%), pain (22.4%), and worried (21.3%); the differences were lowest for angry (11.4%) and tired (10.9%). The finding that parents consistently over-estimated their children's symptoms may be explained in several ways. Children may internalize their symptoms and not be able to express what they are feeling and what their feelings mean; or, parents may be under high stress so they project their own feelings to their children (Martin et al., 2004). Younger children may try to please adults by minimizing their symptoms (Margaret et al., 2002) or believe that in doing so, they would be discharged sooner (Martin et al., 2004). We believe that children and adolescents ages 6 to 21 years are fully capable of reporting what they are thinking and feeling if they are asked these questions by caring health professionals, and believe that their responses will make a difference in the quality of their care.

Children's likes and dislikes about their nursing care were very different from what parents thought their children would like and dislike. Ecological momentary assessment theory suggests that individuals react to in-the-moment experiences (Stone & Shiffman, 1994). Adults interpret nurse behaviors from their own experiences and expectations. Children's experiences include symptoms associated with their diagnoses, painful procedures, strange medical equipment, unfamiliar environment, many different caregivers, and sometimes the absence of their parents.

Limitations

The large sample size (N=496) sometimes resulted in statistical significance when in fact, actual scores between groups were minimal, and not clinically significant. This was a cross-sectional study; a longitudinal design would reveal changes in children's perceptions as their condition changes.

Recommendations

This study confirms previous research findings that parents' and children's perceptions of children's emotions, symptoms, and opinions are not the same. Because parents underestimate the importance of nurse behaviors to their children, hospitalized children should have the opportunity to evaluate the quality of their own care.

Nurses should routinely ask hospitalized children what they like and do not like about their nursing care. We recommend that nurses and hospitalized children converse at least daily about the children's current emotions, including "afraid or scared," "angry," "sad or blue," and "worried" from the Peds-QL instrument. Most importantly, nurses should make appropriate adjustments in the children's care, and communicate this information to other caregivers.

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Table 1.

Hospitalized Children: Demographic and Clinical Characteristics of the Sample (N=496)

Characteristic	n	%
Gender		
Male	244	49.2
Female	252	50.8
Race		
White	362	73.0
Black	100	20.2
Asian	7	1.4
American Indian or Alaskan	2	0.4
Other	25	5.0
Age group		
Young school-age 6-7 years	58	11.7
Older school-age 8-10 years	109	22.0
Adolescence-age 11-14 years	133	26.8
Older Adolescence-age 15-17 years	121	24.4
Late adolescence 18-21 years	75	15.1
Diagnosis		
Gastrointestinal	128	25.8
Neurology	62	12.5
Hematology/Oncology	54	10.9
Pulmonary	52	10.5

Infectious	43	8.7		
Endocrine/Autoimmune	34	6.9		
Genitourinary	30	6.0		
Orthopedic	24	4.8		
Multiple Trauma	22	4.4		
Miscellaneous	21	4.2		
Cardiac	15	3.0		
Behavioral	11	2.2		
	Range	Median	Mode	Interquartile
Hospital day of interview				range
	1 to 337	4	3	
Number of invasive procedures prior to the interview	0 to 216	3	2	
Number of previous hospitalizations	0 to 720	1	0	
Median household income per year	\$14,718	\$37,967	\$34,287	
	to			
	\$95,618			

Table 2.

Comparison of Parents' and Children's Responses of Likes and Dislikes About Their Nursing Care

Nurse behavior	Children (C)		Parents (P)		z	P
	n	%	n	%		
Checks on me often	148	35.8	44	10.7	8.567	<0.001* C>P
Talks and listens to me	136	32.9	92	22.3	3.425	<0.001* C>P
Nice and friendly	134	32.4	114	27.6	1.518	0.129 C=P
Gives me medications	131	31.7	28	6.8	9.090	<0.001* C>P
Gives me things to do	125	30.3	29	7	8.577	<0.002* C>P
Responsive to my needs	112	27.1	35	8.5	7.005	<0.001* C>P
Brings me food or drinks	88	21.3	15	3.6	7.688	<0.002* C>P
Helps me do things	85	20.6	21	5.1	6.658	<0.001* C>P
Takes care of me	71	17.2	54	13.1	1.651	0.099 C=P
Plays with me	52	12.6	16	3.9	4.557	<0.001* C>P
Laughs and jokes with me	48	11.6	27	6.5	2.543	0.001* C>P
Cares about me	19	4.6	28	6.8	1.352	0.176 C=P
Makes me comfortable	68	16.5	50	12.1	1.79	0.074 C=P

Gives me respect and privacy	29	7.0	13	3.1	2.534	0.011* C>P
Uncomfortable procedures	186	47.1	71	18	8.643	<0.001* C>P
Wakes me up	67	17	30	7.6	3.999	<0.001* C>P
Painful experiences	63	15.9	11	2.8	6.335	<0.001* C>P
Not responsive to my needs	52	13.2	56	14.2	0.413	0.680 C=P
Doesn't talk or listen to me	18	4.6	14	3.5	0.721	0.471 C=P
Not nice or friendly	17	4.3	13	3.3	0.744	0.457 C=P
No respect or privacy	14	3.5	11	2.8	0.609	0.543 C=P

* $\alpha \leq 0.05$

Table 3.

Comparison of PedsQL-PF Item Scores Between Hospitalized Children and Their Parents

Symptom	Children		Parents		Chi-square	P
	n	%	n	%		
Afraid or scared	120	29.0	228	55.1	16.965	<0.001*
Sad or blue	139	33.6	254	61.4	17.763	<0.001*
Angry	83	20.0	130	31.4	20.336	<0.001*
Worried about what will happen to me	232	56.0	320	77.3	10.308	0.001*
Tired	303	73.2	348	84.1	26.845	<0.001*
Pain or hurt	228	55.1	321	77.5	50.52	<0.001*

*alpha \leq 0.05

Table 4.

Differences in RCADS Total and Subscale Scores According to Nurse Behaviors that Children Liked and Disliked

	Laughs and jokes		Not nice or friendly		Not responsive to needs		Doesn't talk or listen	
	Yes	No	Yes	No	Yes	No	Yes	No
<u>RCADS item</u>	<u>Mean ± SD</u>		<u>Mean ± SD</u>		<u>Mean ± SD</u>		<u>Mean ± SD</u>	
Obsessive compulsive	42.7±9*	46.7±12.5*	46.7±9.9*	43±9.6*			52.3±10.9*	42.9±9.4*
Generalized anxiety					45.2±10.2*	42.2±9.4*	47.4±8*	42.4±9.6*
Separation anxiety							56.6±13.4*	49.7±10.8*
Depression							53±9.8*	47.3±10.8*
Total anxiety							50.6±9.1*	43.1±10.3*
Total anxiety and depression							51.2±9.3*	43.6±10.7*

*alpha ≤ 0.05

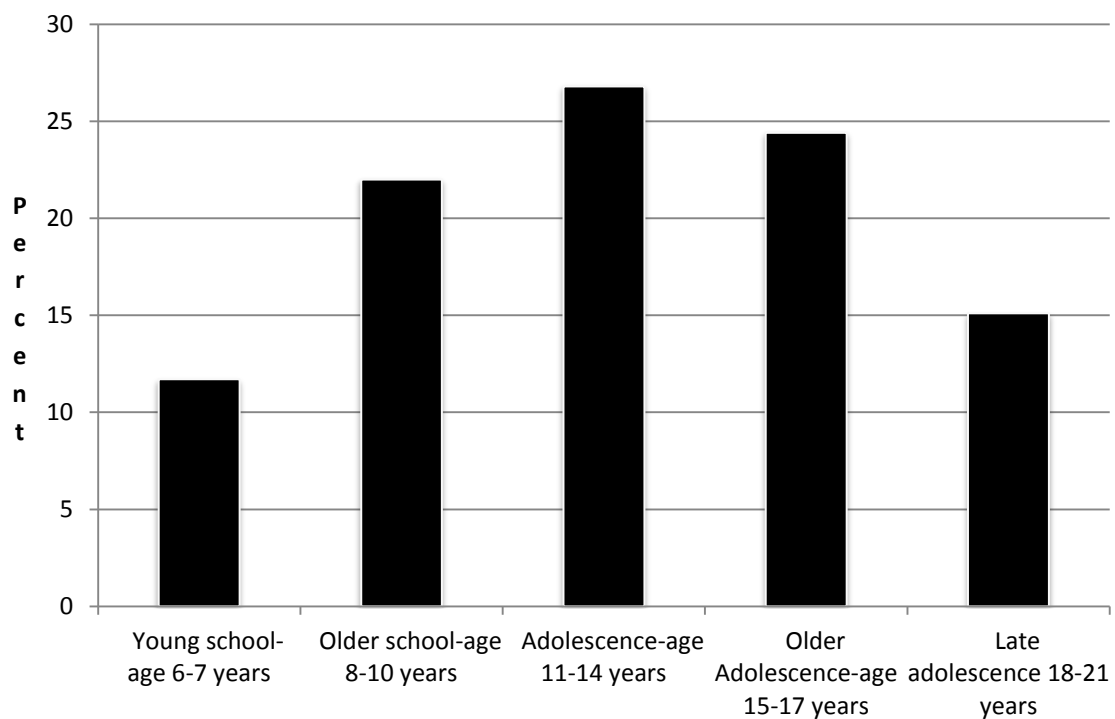


Figure 1. Age group demographics of hospitalized children.

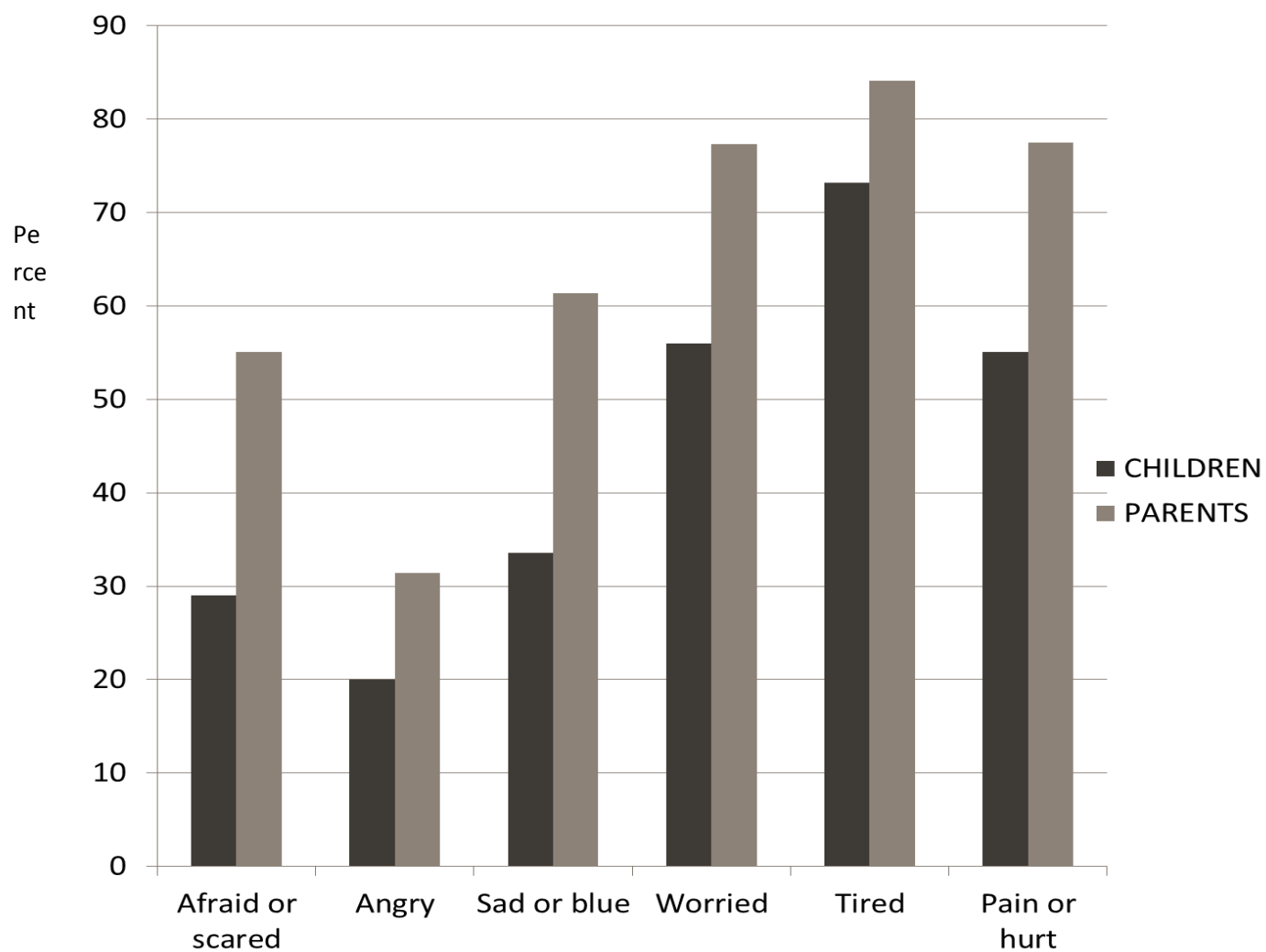


Figure 2. Comparison between children and parents related to positive responses to symptoms of the Peds-QL.